HEALTH AND SPORT COMMITTEE

32nd Meeting, 2015 (Session 5), Tuesday 24 November 2015

Transplantation (Authorisation of Removal of Organs Etc.) (Scotland) Bill

Note by the Clerk and SPICe, Informal Meeting – Faith and belief groups

12 November 2015

Members in attendance – Duncan McNeil MSP, Richard Lyle MSP, Colin Keir MSP

Background

The group included representatives from faith and belief groups. Attendees were:

- Ephraim Borowski (Scottish Council of Jewish Communities)
- Gordon MacDonald (CARE for Scotland)
- Reverend Thomas Boyle (Catholic Parliamentary Office)
- Professor Donald MacDonald (Free Church of Scotland)
- Philippa Taylor (Christian Medical Fellowship)
- Reverend Sally Foster-Fulton (Church of Scotland)
- Gary McLelland (Humanist Society)
- Naren Sood (Edinburgh Interfaith)
- Rev Prof David Atkinson (Scottish Episcopal Church)

Detailed below is a summary of the range of views expressed at the meeting:

- All participants agreed that they support organ donation.
- All participants agreed that they wanted organ donation rates to increase.
- Most participants agreed that it was best to wait until the ‘opt-out’ system had been in place in Wales for a few years to see if organ donation rates increased before introducing it in Scotland.
- The Humanist society however wanted the Bill to pass believing that the move to the ‘opt-out’ system in the Bill would increase donation rates.
- Many of the participant felt that the momentum of increasing organ donations was good at present and that evidence of increases in organ donation rates by moving to an ‘opt-out’ system was “erratic”.
- The ‘opt-in’ rate is apparently rising faster in the UK than anywhere else.
- Most participants felt that organ donation should be seen as a gift and that any move to presumed consent would take that away. Therefore the current informed consent system should remain.
- “The gift of an organ is the greatest single gift that one can give”. Most participants agreed that organ donation must be a gift and cannot be forced. Instead a different means to encourage gifting should be used.
- Some believed that the comfort felt by families after agreeing to organ donation was because it was a gift. If there was a move to presumed consent then this feeling of doing something good could be lost.
- Humanist Society felt that focus should be on the likely increase in donor rates that this Bill could have.
Some noted that a move to an ‘opt-out’ system had actually resulted in a decrease of donation rates in some South American countries.

Concerns were raised by some that the change to an ‘opt-out’ system could actually lead to a fall in organ donation rates as some people do not like being told they have to do something.

Most felt that the move from a publicity campaign to encourage people to ‘opt-in’ to one advising people of their right to ‘opt-out’ was the wrong move and that the focus should always be on the positive aspect.

One participant suggested that there should be a mechanism included in the Bill so that data can be collected and monitored with a review in future to see if the change is working given the Bill did not propose a pilot of the opt-out system.

It was noted that most people want to be virtuous and make the positive choice to donate organs. They contended that this contributes to society and the common good.

Concern was raised by one participant that if a person is compelled to give organs by the state then where could this lead; what else could one be compelled to do by the state. They explained that this could be a frightening underlying principle.

The Humanist Society believes that the change to an opt-out system is a mechanism for by which a person can decide what happens to them once they are deceased. They would have concerns about the ability of people to override a deceased person’s wishes. They consider that this Bill puts the onus on the individual to make a choice.

Many participants felt that you would lose autonomy over your own body by having to ‘opt-out’ which not everyone would be able to do.

One person raised concerns about the Bill being introduced as a Members Bill and believed such an important change should be initiated by the Scottish Government.

**Bill proposals**

*Authorised Investigating Person (AIP)*

Concerns were raised about what the role of an authorised investigating person (AIP) would be and whether it would replace the role of a Specialist Nurse on Organ Donation (SNOD). Participants explained that SNODs are well trusted and have the best interest of the family.

Some had concerns that there needs to be a better definition or “reasonable time” for AIPs to contact all the proxies or nearest relative.

Questions were raised by some participants on what the relationship between a SNOD and an AIP would be. It was felt that the relationship between a SNOD and the family was too important to the whole process and should not be removed.

Some participants were concerned about which professional would be the AIP. If it was a health professional it was noted that as they are generally busy with clinical work, they would be very stretched to carry out the investigations required.
• Concern was raised that as an AIP could be a very busy health professional if there was ambiguity around whether someone wanted to donate, they may decide the person did not want to donate.
• A concern was raised about how the doctor/patient relationship could change if an ‘opt-out’ system was introduced and that it could be stretched if targets were proposed which had to be met.

Equality Issues

• Some participants expressed a worry that any campaign to highlight a change from ‘opt-in’ to ‘opt-out’ would not reach all people, especially those with mental incapacity or with fragile family issues.
• A participant also highlighted how it would be ensured that people who did not understand or speak English are aware of the change to an opt-out system.
• A concern was raised about how to ensure that those who lacked capacity could ‘opt-out’. It was felt that this issue should be addressed on the face of the Bill and not just in the Policy Memorandum.

Proxy

• There was concern that a proxy could overrule a family decision on organ donation.
• A concern was raised about the role of the family in the process. It was felt that this role should be in the Bill to stop any undue distress and that the family role must be protected.
• Many felt that the role of the family was ambiguous in the Bill and that their views must be heard and taken into account.
• It was noted that if human beings are moral subjects then they should always have a choice. Upon death your body becomes the property of the spouse/family and as such they have a right to say what happens to your body.
• Any issue highlighted was whether there is a role for conscientious objections from medical staff. Can they stop any donation if the family are not being heard and are very upset?

Residential Status

• Most were not clear on how the residential status of the organ donor could be established to see whether the 6 month residency rule in the Bill was met such as with students or temporary workers.

Publicity Campaign

• Some felt that any publicity campaign should run for at least 12 months rather than the 6 months proposed in the Bill given the significance of the change.

Persons to whom the Bill applies

• Some believed that the Bill should be applicable to those 18 and over rather than 16 and over.

 Alternatives to the Bill if it wasn’t passed
• Increase the education provided about the ‘opt-in’ system to ensure that more people are aware of the system so that the first time they discussed organ donation with family was not at the time of a death.
• There is a need for the issue to be discussed more widely in society and made part of everyday discussions. It is only once the issue is properly discussed more openly can informed consent system be more successful.
• It is believed that the more openly the issue is discussed then the higher donation rates will rise.
• One participant suggested that your views on whether you want to donate your organs should form part of the anticipatory care planning process and should be recorded on your Anticipatory Care Plan when you complete one.
• Some suggested that an increase in the number of specialist nurses and regional co-ordinators would help to increase donation rates.

The Christian Medical Fellowship agreed with the Convener to provide additional written evidence.